

Alzheimer's/Dementia Respite Program Report

State Fiscal Year 2000

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Introduction

In July of 1998 a new statewide initiative began offering respite care resources to families caring for a family member with Alzheimer's Disease or a related dementia. In early 1998 the Champlain Valley Agency on Aging (CVAA) partnered with the Department of Aging & Disabilities (DA&D) to pilot the concept. The statewide program has since expanded coverage to all regions, through four of the five Area Agencies on Aging and Rutland Community Programs with co-sponsor, Bennington Counseling Services, which is currently administering the program for the southwestern section of Vermont. During both State Fiscal Year (SFY) 1999, and then again during SFY 2000 the Legislature provided \$200,000 to fund this initiative. During SFY 2000, 217 families received up to \$2,000 per year to provide support for the caregiver. Caregivers were able to decide what would best provide relief for them. This included, but was not limited to; personal relaxation, dining out, entertainment, travel and hiring respite caregivers.

The data in this report represents final statistics from the second full year of expanded coverage. The program is now utilized strongly through the Champlain Valley Agency on Aging (CVAA), the Northeastern Vermont Area Agency on Aging (NEVAAA), and through the Central Vermont Council on Aging (CVCOA). It is gaining strength through the Council on Aging for Southeastern Vermont (COASEV). At the beginning of SFY 2001 Rutland Community Programs became the grantee for Southwestern Vermont where the program has also experienced encouraging growth.

During SFY 2000, of the 217 recipients served with a diagnosis of dementia, 59% were female and 41% were male. 78% of the recipients were 75 years of age or older. Slightly over 45% of the recipients were cared for by a spouse. Daughters and sons provided another 40% of the care. Although 49% of the caregivers reported that it was moderately to extremely likely that their loved one would require out-of-home placement within six months, only 8% or 19 recipients were actually placed in a nursing home during the grant period. As Susan Gordon, Executive Director of the Alzheimer's Association, Vermont Chapter has indicated, "The Respite Program is a success. People are receiving respite. People who previously would not have been able to obtain respite are asking for and receiving assistance. Grant recipients have trouble believing that they are entitled to receive the grant money and some think they must save it for emergencies. No one just gives them money to care for themselves! The most important aspect of the respite program, however, is the increasing awareness that dementia care requires a comprehensive system of care and support for the person with dementia as well as all those who care for them."

In summary, it is important to note that the Dementia Respite Grant Program continues to gain strength. While the Council on Aging for Southeastern Vermont (COASEV) had a 33% carry over at the end of State FY 2000, in the first quarter of State FY 2001, COASEV quickly obligated all of the carry over for grant recipients.

A new grantee, Rutland Community Programs, with co-sponsor Bennington Counseling Services, is currently covering the southwestern portion of the State furthering the important work begun by the Southwestern Vermont Council on Aging (SVCOA). Rutland Community Programs obligated \$36,766.56 in respite funds for recipients in southwestern Vermont in the first quarter of State FY 2001.

Recipients continue to state that the Dementia Respite Grant Program allows them to some time to care for themselves so they are better able to continue caring for their loved ones at home. A sampling of actual comments concerning the need for respite is provided below.

- “I need a break – I have not had one day off of care giving in one year.”
- “Peace of mind to know he can stay at home while I am in the hospital.”
- “The respite funding has allowed me to have some significant respite from the 24 hour/7 days a week care. Without the program it would be difficult to have a real break.”
- “It has given me breathing room. No longer on the edge fiscally and it is nice to have dependable respite care when needed.”
- “It will make all the difference in the world.”
- “It made me feel relaxed and relieved to have someone watch him and I don’t have to worry.”
- “It gets very difficult when she doesn’t sleep, because I don’t sleep. I am worried what will happen if she stops eating again. When I am rested I manage care giving much better.”
- “It’s getting more and more difficult. I have to do everything myself which is a huge burden and weight on me.”
- “I feel very isolated and am in great need of social contact. I need to take some time off and renew.”
- “It just gives me a great lift and new outlook and the courage to go on.”
- “It gives me a break and freedom of not feeling completely tied down. This program has been such a help to me.”
- “I don’t get as discouraged and know I have a break in sight to get away from the situation.”

- “I just want to thank you and the Respite Grant Program for allowing me to get out and enjoy myself and to help me do a good if not better job at caring for my dad.”
- “I am sure that I would become resentful if I had to continually deny myself a chance to socialize and be with friends.”
- “It has allowed me to deal with the stress and strains of caring for my father even with the fact that he has become less able to do things he could do earlier on in my care giving.”
- “I was able to pay for care for my mom (she needs 24 hr. a day care) so my husband and I could visit our daughter in Virginia – something we hadn’t been able to do for four years.”
- “The respite funding has made a difference because it helped me to reduce stress and make me feel good about myself and what I am doing for my mom.”

All grantees will be receiving an additional combined total of \$158,130 in funds for FY 2001. This is due to the State of Vermont receiving the Administration on Aging’s (AoA) *Alzheimer’s Disease Demonstration Grants to States Program*. This is a three year grant, which could bring as much as \$1 million to the State of Vermont. This three year grant project will focus on improving the capacity of Vermont’s Adult Day Centers (ADC) to deliver quality care to individuals with Alzheimer’s Disease and related disorders, funding direct services, developing support services for individuals with early stage dementia, increasing the early detection of dementia through education and use of a screening tool, and public education. The additional funding will allow the State to expand the income limits of the program for recipients from 200% to 300% of poverty, thus allowing more people living with dementia and their caregivers to be served. The Dementia Respite Grant Program is a significant link in the chain of long-term care services to support “aging in place” in spite of the limitations of chronic disease and illness.

Statistical Information

I. Demographics: Persons with a Dementia (Clients)

		CVAA	NEVAAA	CVCOA	SVCOA	COASEV	TOTALS # % *	
SEX	FEMALE	31	17	27	23	31	129	59%
	MALE	31	18	21	8	10	88	41%
AGE	<60	1	0	3	1	1	6	3%
	60-65	6	0	2	0	1	9	4%
	65-74	12	1	7	7	7	34	16%
	75-84	24	23	20	17	17	101	47%
	85+	19	11	16	6	15	67	31%
DIAGNOSIS	AD*	36	25	40	23	28	152	70%
	NON AD*	26	10	8	8	13	65	30%
HOSPITALI- ZATION		6	35 (days)	23	17	131 (days)		
INCOME	< \$750	19	4	20	11	14	68	31%
	\$750- \$1,000	15	10	10	10	11	56	26%
	\$1,001- \$1,500	20	11	9	7	16	63	29%
	\$1,501- \$1,923	8	10	8	3	9	29	13%
	\$1,924- \$2,170	0	0	1	0	0	1	1%

*Alzheimer's Disease

*Non-Alzheimer's Dementia

II. Their Caregivers

Agency	CVAA	NEVAAA	CVCOA	SVCOA	COASEV	Totals	
						#	%
WIFE	22	16	15	5	12	70	32%
HUSBAND	7	6	4	5	6	28	13%
DAUGHTER/ SON	19	13	25	14	13	84	39%
IN-LAWS	6	-	-	3	-	9	4%
GRAND- CHILD	4	-	-	-	-	4	2%
SISTER	2	-	1	-	-	3	1 %
NIECE	-	-	-	1	-	1	.5%
GUARDIAN	-	-	-	1	-	1	.5%
FRIENDS	-	-	3	-	-	3	1%
OTHER	2			2	10	14	7%
TOTALS	62	35	48	31	41	217	100%

III. Stated Likelihood of Out-Of-Home Placement of Client Within 6 Months

Agency*	Extremely Likely	Moderately Likely	Extremely Unlikely
CVAA	5	17	40
NEVAAA	4	15	16
CVCOA	7	18	23
SVCOA	15	10	6
COASEV	1	13	27
Totals	32 or 15%	73 or 34%	112 or 52%

*Please note that agency abbreviations are spelled out on page 6.

IV. Clients Actually Placed in Nursing Home

Agency	Client Placed In Nursing Facility
CVAA	9
NEVAAA	4
CVCOA	3
SVCOA	0
COASEV	3
Totals	19 or 8%

V. Referral Sources

	CVAA	NEVAAA	CVCOA	SVCOA	COASEV	Totals	
						#	%*
AAA	31	23	41	18	24	137	63%
ADULT DAY	13	2	2	1	4	22	10 %
ALZHEIMER'S ASSOCIATION	3	1	-	3	-	7	3%
DOCTOR	-	1	1	1	-	3	1%
FAMILY/ FRIEND	-	-	1	0	1	2	.9%
HH	8	8	1	5	5	27	12 %
NEWSPAPER	-	-	-	2	5	7	3%
OTHER	7	-	2	1	2	12	6%
Totals	62	35	48	31	41	217	98.9%

*In some cases percentages may not total 100% due to rounding.

VI. Financial Accounting

Agency	Grant Amount	Number Served	Spent	Admin	Carry Over for 2000 & %
CVAA	\$72,031.40	62	\$63,381.00	\$8,274.00	\$6,240.00 or 9%
NEVAAA	\$38,168.20	35	\$33,118.48	\$1,655.92	\$5,049.72 or 13%
CVCOA	\$53,399.15	48	\$41,007.79	\$4,748.00	\$7,561.36 or 14%
SVCOA	\$66,369.08	31	\$36,482.68	\$3,881.28	\$30,143.80 or 45%
COASEV	\$58,140.00	41	\$36,676.13	\$1,990.58	\$19,473.29 or 33%
Totals	*\$288,107.83	217	\$210,666.08	\$20,549.78	\$68,468.17 or 24%

*** \$10,000 was provided to the Alzheimer's Association, Vermont Chapter for outreach, support and education for caregivers.

- Total grant amount includes FY 2000 award and FY 1999 carry over.

Agency Abbreviations

CVAA - Champlain Valley Agency on Aging
NEVAAA – Northeastern Vermont Area Agency on Aging
CVCOA – Central Vermont Council on Aging
SVCOA – Southwestern Vermont Council on Aging
COASEV – Council on Aging for Southeastern Vermont